

**Virginia Genetics Advisory Committee**

**Monday, September 29, 2003**

**10:00 a.m. – 12:00 Noon**

(12 Noon: Optional Tour of DCLS)

**Division of Consolidated Laboratory Services**

**Room T-23**

**600 North 5th Street**

**Richmond, VA 23219**

**Telephone (804) 648-4480**

**MINUTES**

**Present:** Willie C. Andrews—DCLS; Ether Richardson, LPN—VDH; Joann N. Bodurtha, MD, MPH, Chair—VCU; Mary Ann Discenza—DMHMRSAS; Laura Duncan, MPH, RD—VCU; Sara Long—March of Dimes Va. Chapter; James (“Jim”) L. Pearson, DrPH—DCLS; Virginia (“Ginny”) K. Proud, MD—CHKD; Jene O. Radcliffe-Shipman—VDH; Charlie Stevenson, MS—DCLS; Suzanne Trotter, MS, RN—VDH; Sharon Williams, MS, RN—VDH; William (“Bill”) G. Wilson, MD—UVA Health Sciences Center; Melody Persinger Yeargin—CHKD; Joanne S. Boise, MSPH—VDH

**Guests:** Jennifer Lee—VCU Genetic Counselor

**Absent:** Nancy Bullock, RN, MPH—VDH; Nancy Ford, MPH, RN—VDH; Kathleen M. Link, MD—Inova Fairfax and Fairoaks Hospitals; Karen Meister, MS, CGC—VCU/VDH; Walter Nance, MD, PhD—Va. Newborn Hearing Screening Cmt.; Arti Pandya, MD, MBA—VCU; Gwen Smith, RN, MSN—VDOE; Harvey Stern, MD, PhD—Genetics and IVF Institute; Joan Corder-Mabe, RNC, MS, OGNP—VDH

**Recorder** Suzie Trotter

Time	Item	Person	Notes/Plan
10:00 to 10:15	1. Welcome a. Introductions b. Approval of 6/23/03 Minutes (emailed 6/29/03) c. Review of Agenda (emailed 9/5/03) d. Membership (revised 6/26/03): Circulate list for corrections. (emailed 6/29/03)	a. J. Bodurtha b. J. Bodurtha c. J. Bodurtha d. N. Ford	a. None b. Approved as written. c. No changes, tour will commence at end of meeting. d. Circulated.
10:15 to 10:40	2. Updates: Agencies, Organizations, Grants a. VDH: Virginia Genetics Program b. VDH: Virginia Sickle Cell Awareness	a. S. Williams b. J. Shipman c. J. Pearson d. K. Meister e. J. Bodurtha f. V. Proud g. S. Long	a. Continuing to work for a viable solution for No. VA Genetics contract. Establishing 3 <sup>rd</sup> metabolic treatment contract with EVMS this year. b. September was Sickle Cell Awareness month; shared marketing efforts and Governor’s proclamation. Received

	<p>Program</p> <p>c. DCLS</p> <p>d. VDH: CDC Grant “Va. Congenital Anomalies Tracking and Prevention Improvement Project”</p> <p>e. VCU: MOD Grant “Genetic Services and Education-Assessment of Needs”</p> <p>f. EVMS: CDC Grant Application “Genetic Services for Infants with Congenital Hearing Loss in Va.”</p> <p>g. MOD: Organization and Advocacy</p> <p>h. DMHMRSAS: Part C of IDEA: Infant &amp; Toddler Connection of Virginia</p> <p>i. DOE</p>	<p>h. M. Discenza</p> <p>i. G. Smith</p>	<p>\$16,000 from United Way to pay for screening services; partnered with Sickie Cell Association of Hampton Roads.</p> <p>c. Kudos to C. Stevenson and his staff for continuing services throughout Hurricane Isabel. 3 tandem mass spectrometry (MS/MS) instruments have been ordered; to be delivered in October 2003. MCAD deficiency testing and follow-up implementation is on target for March 2004. Per Dr. Pearson, “best lab in the country!”</p> <p>d. K. Meister on extended leave—hospital record review initiated, will continue with help in interim of J. Lee. Discussions held with Welligent for data entry. Folic Acid campaign with March of Dimes will continue through November focusing on private providers. VDH PSGS will follow up VDH Division of Dental Health’s folic acid campaign (distribution of Folic Acid table-top display board and cards) with additional distributions.</p> <p>e. Education Assessment Surveys have been mailed.</p> <p><b>a. Plan:</b></p> <ul style="list-style-type: none"> <li>• <b>All members</b> will complete and return survey if received a survey.</li> </ul> <p>f. V. Proud reported that EVMS expects to be notified about approval before October 1, 2003.</p> <p>g. Finalizing advocacy efforts. FAMIS expanding with pregnant women as a high priority.</p> <p>h. Piloting the VISITS At-Risk module automatic referral project at CHKD and nine Central Points of Entry for the Part-C Early Intervention system in eastern Virginia. Hearing screening is the initial prompt. Pilot is being extended to address problems before implementation statewide. Discussed the challenge of retaining physicians. Why do child find if have no resources to see kids? Media: have Governor’s attention, and he has made it a priority.</p> <p>i. No report.</p>
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10:40 to 10:50	3. Updates: Virginia Genetic Centers a. VCU b. EVMS c. UVA d. RFP Northern Virginia	a. J. Bodurtha b. V. Proud c. B. Wilson d. S. Williams	a. Financial concerns like other sites. 6 genetic counseling students, no fellow this year. Biggest challenge—keeping program/services going without proper funds. Meeting with Anthem on Monday as they plan to cover some additional testing beyond their currently-covered genetics services. b. Working to get metabolic treatment center contract with PSGS. One genetic counselor moved and replaced; Emily Gutter is new. Need clinical geneticist. Melody is able to give ½ time nutritional support to genetics. Working toward specialty disorder treatment. Have endocrinologist doing IV disphosphatase infusions. Continue working with MPS1 w/ genzyme one day a week w/ STPU—nurses trained. c. Financial stress in the pediatric department due to major funding of Medicaid. Held Turner Syndrome Day and Huntington Dis. Symposium. Continue with metabolic treatment program as well as other specialty disorder treatments. Ready for MCAD deficiency. Need new counselor. d. Northern Virginia contract is expiring. Plan: short-term contract while finding plausible solution. Work in progress.
10:50 to 11:00	4. Review/Modify: VaGAC Infrastructure (revised 6/23/03) (emailed 6/29/03)	J. Bodurtha with group discussion	a. V. Proud nominated Pat Dewey, VEHDI Program Manager, as a representative to VaGAC for hearing program (in additional to Walter Nance). <b>Plan:</b> • <b>N. Ford</b> will contact P. Dewey. b. Discussed need to make current work groups components of broader, more generic subcommittees because some issues, such as newborn screening, would not be addressed under current structure. There was consensus to name subcommittees; organize the State Genetics Plan, Tandem Mass Spectrometry, and Parent Involvement work groups under subcommittees; and change VDH Contractors Work Group into a subcommittee. <b>Plan:</b> • <b>N. Ford</b> will make the following

			<p>changes to the Infrastructure plan and distribute revised plan.</p> <p>(1) <i>Genetics and Public Health Subcommittee</i></p> <p>(i) State Genetics Plan Work Group</p> <p>(ii) Membership: Current work group members and others if indicated (e.g., health district director).</p> <p>(2) <i>Newborn Screening Subcommittee</i></p> <p>(i) MS/MS Work Group</p> <p>(ii) Membership: Current work group members, A. Kumar, K. Link, J. Shipman, and others if indicated.</p> <p>(3) <i>Community Partnerships Subcommittee</i></p> <p>(i) Parent Involvement Work Group</p> <p>(ii) Membership: Current work group and others if indicated.</p> <p>(4) <i>VDH Contractors Subcommittee</i></p>
11:00 to 11:50	<p>5. Work Group Reports</p> <p>a. State Genetics Plan</p> <p>b. Tandem Mass Spectrometry</p> <p>c. Parent Involvement</p> <p>d. VDH Contractors</p>	<p>a. J. Bodurtha</p> <p>b. W. Andrews</p> <p>c. K. Meister</p> <p>d. S. Williams</p>	<p>a. and c. Statewide birth defect conf continues with March of Dimes partnership proposed. Challenge continues to make genetics operational in health department. Parent involvement—good plan developed by K. Meister. Jennifer Lee will temporarily help move it forward. Expect to have parents attend spring VaGAC meeting.</p> <p>b. Postponed due to Hurricane Isabel; will meet today. Expected needs: specific fee increase will be determined after budget analysis (fee estimate was developed during legislative session). 3-scientist positions open. Educational print material needs to be developed.</p> <p>d. Finalized quarterly reporting form. 1<sup>st</sup> quarter ends tomorrow; look for new reports in November 2003.</p> <p><b>Plan:</b></p> <ul style="list-style-type: none"> <li>• <b><u>S. Williams</u></b> will email new report to contractors.</li> </ul>
11:50 to 11:55	<p>6. New Business</p> <p>a. VaCARES 10-Year Report:</p>	<p>a. N. Ford</p> <p>b. All</p>	<p>a. VDH received feed back from one health district, which has an increase in birth defects shown by data. Feedback form,</p>

	<p>Feedback</p> <p>b. Travel Reimbursement</p> <p>c. VDH Move</p>		<p>which appears in the back of the report, was distributed.</p> <p><b>Plan:</b></p> <ul style="list-style-type: none"> <li>• <b>All members</b> will complete and return feedback form.</li> </ul> <p>b. Travel reimbursement forms were distributed.</p> <p><b>Plan:</b></p> <ul style="list-style-type: none"> <li>• <b>All members</b>, if applicable, will complete and return Travel Expense Voucher to N. Ford for reimbursement for today's meeting.</li> </ul> <p>c. VDH will be vacating Main Street Station in December 2003. Most staff will be moving to the Madison building. The Division of Child and Adolescent Health, including the Virginia Genetics Program, will be located on the 8<sup>th</sup> floor. All staff members will have new addresses and new phone and fax numbers.</p> <p><b>Plan:</b></p> <ul style="list-style-type: none"> <li>• <b>N. Ford</b> will send new contact information as soon as available.</li> </ul>
11:55	<p>7. Next Meeting</p> <p>a. Date</p> <p>b. Time</p> <p>c. Location</p>	J. Bodurtha	<p>a. Date: March 29, 2004, or April 5, 2004, depending on N. Ford's availability.</p> <p>b. Time: 10 a.m. – 12 noon.</p> <p>c. Location: Madison building if available, including a tour. Alternate location: DCLS.</p> <p><b>Plan:</b></p> <ul style="list-style-type: none"> <li>• <b>W. Andrews</b> will reserve a room in DCLS as back-up if needed</li> <li>• <b>N. Ford</b> will confirm with W. Andrews on meeting date and location.</li> </ul>
12:00	<p>8. Adjourn</p>	J. Bodurtha	<p>Many thanks for the hospitality from Dr. Pearson and the DCLS staff for the accommodations and tour of the new facility today.</p>